

Cultivating Identity: Emerging Adults with Disabilities

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Abstract

Emerging adulthood is a recent concept in psychology that encompasses individuals from ages 18-25. Research has shown that the development of an individualized identity is of great importance in this period of the life. This project explores the elements involved in cultivating an identity as an emerging adult, as well as the role those elements play in the lives of emerging adults with disabilities. My observations were constructed upon an internship with the Transition Options in Postsecondary Settings (TOPS) program for students with intellectual disabilities at The Ohio State University. I have based this project on the works of emerging adulthood scholar Jeffery Arnett, as well as those of disability studies scholars Andrew Solomon and Tobin Siebers. In addition, I use concepts discussed in *Think College*, a guidebook for individuals leading the TOPS program, and the International Classification of Functioning, Disability, and Health (ICF) model, to aid in understanding the connection between identity and disability. It is my hope that this project will eventually lead to the personal growth of emerging adults with disabilities as they become successful in higher education settings and in life.

Introduction

The transition into adulthood is a time of discovering one's identity. This holds true not only for persons without disabilities but also for those with disabilities. Historically, society has defined the worth and identity of those with disabilities solely by their disability. Society brought the disability to the forefront and neglected the individual. Specifically, those with intellectual disabilities were called "mentally retarded" meaning they severely lacked the intricate ability to think, act or speak at a higher level. In disability studies, this is called the medical model of disability. Presently, those in the disability studies movement are striving towards the social model, which places the responsibility of how the individual is treated by the society. In addition, the disability studies movement places the individual first and states that the disability is only a *part* of their identity.

Through personal interactions with individuals with disabilities in a higher academic setting, I have observed these individuals as they strive to incorporate their disability into their unique identity. The TOPS program at The Ohio State University served as the context for my observations. The program's purpose is to:

empower students [with intellectual disabilities] to become self-determined adults by providing them [with] college experiences including participation in college classes, internships, employment, and campus social life that are customized to each student's interests and needs. Students in TOPS receive instructional support through "educational coaches," employment support through "job coaches" and daily living/recreational support through "life skill coaches." Students receive career counseling and job development supports that are necessary for successful inclusion in the campus community. Through a vast network of supports including families, OSU students,

faculty, and professionals, the TOPS program has developed into an opportunity for individuals with disabilities to experience college, participate in academics, build independent living skills, and gain experience and employment. (TOPS Program Transition Services, 2014)

Supervisors for this program regularly work with the TOPS students to help them feel comfortable both advocating for themselves as well as disclosing their disability to those around them. These skills are both key because they place the power of disability disclosure in the hands of the individual. Any individual with a disability must be confident enough in their multidimensional identity to provide their peers with an explanation of their disability, when the circumstance calls for it. It is up to the individual to show those around them that their disability is an aspect of their identity, and not their identity as a whole.

This is important because the reverse of the disclosure of disability involves putting the disability into a “closet”. In his book *Disability Theory*, Tobin Siebers expounds upon this concept when he says:

Closeting involves things not merely concealed but difficult to disclose—the inability to disclose is, in fact, one of the constitutive markers of oppression. The epistemology of the closet complicates the usual understanding of passing because it disrupts the structural binary that represents passing as an action taking place between knowing and unknowing subjects. The closet often holds secrets that either cannot be told or are being kept by those who do not want to know the truth about the closeted person. (Siebers, 2008)

He continues by instead proposing a way of thinking of disability as a masquerade. This form of disclosure purposefully pulls disability to the forefront and overtly marks it as one's identity. I propose that this idea is not probable for individuals with disabilities in a higher

academic setting. Within such a setting there is a spectrum of individuality and conformity. The students are on a journey of uncovering and coming to terms with their own personal self.

It is also important to briefly discuss those with physical disabilities here due to the fact experiences may be different for this subgroup. These individuals may encounter barriers that are not otherwise pertinent to those with “normative” bodies. This is due to the fact that their disability is more strongly correlated with their bodies. Seibers states that the more visible a disability is, the more it is repressed and forgotten by society due to the society’s *ideal ology of ability*. (Seibers, 2008). It is interesting that he says this because it alludes to the concept that the type of disability one has effects the types of experiences faced while cultivating identity.

Rosmarie Garland-Thompson also discusses the deconstruction of physical bodies from a social perspective. One of the primary goals of her book is to shift the physically disabled body from “pathology to more of an identity” (Garland-Thompson, 1997). In other words, this is a shift in perspective from a social deviance for the sake of difference, to a social deviance for the sake of an individual’s identity. She goes a step further and says that this deviance ought to be viewed in the same light as that of ethnicity. Minority ethnicities are social deviances from the norm (or governing majority), however societal scrutiny does not look deeper than that. Society acknowledges this difference and accommodates for it when needed. Physical disabilities ought to be treated by society in this same way.

Now the concept of disability *identity* is something that has only recently become prevalent in the field of disability studies. Andrew Solomon discusses the relationship between disability as identity or disability as illness in his book *Far from the Tree*. He states that this relationship is a false dichotomy because illness disparages a way of being whereas identity does the opposite (Solomon, 2012). He asks whether there is room in the cultivation of identity for the

term “illness”. Is it possible that perhaps through the acknowledgement or acceptance of the term illness, identity emerges? His personal stance is that neither identity nor illness can coexist without one minimizing specific and important aspects of the other. This is something to consider when in relation to individuals with disabilities in a higher academic setting.

In the first chapter his book, Solomon also discusses a term called horizontal identity. He defines horizontal identity as some aspect of identity the child has the parent does not, such as sexual orientation or disability. Furthermore, horizontal identity, he states, is discovered through interaction with peers (Solomon, 2012). In direct relation to this, vertical identities are traits that children and parents share (such as ethnicity). Furthermore, he illustrated how the cultivation of his own identity came through first the rejection *then* the acceptance of his own horizontal identity.

This begs the question regarding exactly how one comes to terms with this horizontal identity. In a Ted Talk by Solomon he mentioned three tiers that he believes leads to the acceptance of identity: Self-Acceptance, Family Acceptance, and Social Acceptance. (Solomon, 2013). While he did not go into detail about these three tiers, I have ascertained that there are three steps to the acceptance and cultivation of disability horizontal identity. 1. Awareness. Children become aware of their difference, perhaps at a young age. 2. Acknowledgement and realization. I think this is step where individuals begin to intellectually process and think through how they differ from their peers/families. 3. Knowledge of self. Specifically, I am referring to how one chooses to react to this knowledge of self.

I believe the individuals discussed in this paper have progressed through steps one and two and are currently working through step three. Most of the students in the program have intellectual disabilities that may not be explicitly apparent and in turn may find themselves

assimilating with traditional students through "passing". "Passing" occurs when an individual with a disability integrates themselves to the environment they are in. Seibers states that passing is possible not only because people have sufficient genius to disguise their identity but also because society has a general tendency to repress the embodiment of difference (Seibers, 2008).

Witness of this tendency can be seen in the overarching population of those with disabilities as well. There seems to be a hierarchy in this population based on those who are "less disabled". Two scenarios provide examples of this phenomenon: one involving the film *Murderball* and the second involving a scenario involving a student in the TOPS program. *Murderball* is about a team of para-Olympians who play full contact rugby. During one scene, a team member is retelling a story about attending his girlfriend's friend's wedding. At the reception, there were people who would come up to him asking about his disability but they would treat him as though he had some sort of mental disability as well (Rubin, 2005). As he recounted this incident, he appeared disdainful that individuals in society assumed his use of a wheelchair was associated with an intellectual disability as well. Furthermore, he seemed adamant about asserting to the wedding guests that he did not have an intellectual disability.

Similarly, during an encounter an individual from the TOPS program, the individual decided to use the elevator instead of taking the stairs. Also waiting for the elevator was a man who used a wheelchair, and who was nonverbal and making loud noises. After waiting with the man for a short time, the individual changed his mind and decided to take the stairs. Once in the stairwell, he began to express distaste about the man's presence, proclaiming he was happy he did not have to get into the elevator with "that guy". By the way he continued to speak, it was evident he did not place himself, or his disability, on the same level as this other individual. This alludes that there may be a hierarchy amongst the disabled population. In both scenarios, each

individual did not want to associate himself with a disabled identity that was less like the societal norm.

The problem for individuals with disabilities in a higher academic setting lies in the fact that individuals with disabilities are not just like the societal norm. They are in a betweenity because they are students in a higher academic setting- but with the added dimension of a disability. The relationship between the individual and disability as a part of their identity is one of the most important aspects in whether a student chooses to disclose their disability. This applies to individuals whose disabilities are visible, as well as those whose disabilities are invisible. The questions I then propose are: how do these individuals with disabilities treat their disability stage of their development? Do characteristics of emerging adulthood provide an explanation for their actions?

This research project will connect aspects of disability identity to those of emerging adulthood identity development. Emerging adulthood is a term coined by Jeffery Arnett in the year 2000. It signifies the stage of development between adolescence and young adulthood, and represents individuals 18-25. This stage is of exceptional importance in post industrialized societies due to a greater number of individuals postponing having a family and holding a secure job in lieu of pursuing a higher education degree. The basis for this concept of emerging adulthood stemmed from the earlier works of Erik Erikson. Although he never explicitly defined the period of emerging adulthood, he did create a term called "psychological moratorium". During psychological moratorium, the individual is free from responsibility whilst they decipher their roles in society (Arnett, 2002).

According to Arnett, there are five features of emerging adulthood that characterize this stage of development: identity explorations, instability, focus on self, feeling of in-between and

of possibilities (Arnett, 2006). Identity explorations refer to the ways in which the emerging adult explores areas of work and love in their life. Instability occurs due to the increased amount of consideration for possibilities, as well as the changes that happen as a result of pursuing the possibilities. Now identity issues are present here because the individual must know oneself before making final commitments.

The increased focus on self-causes identity issues because it draws the individuals' attention inward and causes them to question who they truly are. An increased amount of self-focused behavior is a result of less obligations and commitments. Arnett stated that this self-focused behavior is not to be confused with self-centeredness. He found that these individuals can actually be less self-centered, specifically as they begin perspective of their parents shift from authority figure to actual people (Arnett, 2006).

The feeling of being in between is due to the fact that most emerging adults are not fully independent and self-reliant. They are going through a time of recentering. Recentering, according to Jennifer Tanner, is a shift in societal contexts. During adolescence, there was a great amount of influence from parents and family, primarily due to the fact that the child was still at home. However as the individual starts to develop a greater sense of autonomy, the environmental influence in their lives shifts to include coworkers, friends, and classmates (Arnett, 2006). Emerging adulthood is also a mark of increased possibilities about what the future may hold. Such possibilities include future optimism and an opportunity to turn their lives in a more positive direction, especially if their home life was less than favorable (Arnett, 2006). Ultimately, during emerging adulthood have the most amount of ability to mold their lives and cultivate their identity as they see fit.

Case Studies

Introduction

Interactions with subjects occurred during audited courses at The Ohio State University. The focuses of courses were on career development. Classes met in the Younkin Success Center two to three times a week. Average class size was approximately 15 persons. Class was structured around lectures however due to the smaller class size there was a greater amount of interactions with classmates and professor. Courses occurred over the span of one (1) semester or sixteen weeks for each subject. Total combined length of evaluations was one (1) year.

My role was an educational coach. The purpose of an educational coach was to provide academic support to subject and included a variety of responsibilities. First, I accompanied subject to the audited course. The purpose of my presence was not to play an active role in the course but to provide the supports necessary for maximum learning capacity for subject. These academic supports were constructed by the subject and their support team at the beginning of the semester and reviewed once every two weeks during an individualized meeting with the subject and team. Specific examples of supports I provided included: note taking, transcribing subject responses for assignments, and clarifying instructions given by lecturer during class session.

Secondly, I was responsible for facilitating a one hour meeting with subject once a week. The purpose of the meetings was twofold. First, they were a time for the educational coach to provide individualized tutoring on all course assignments. Secondly, they provided an opportunity for discussion about progression, or lack thereof, of semester goals. These goals were constructed during the individualized meetings with support team at the beginning of the semester. Examples of goals included: their level of involvement in class activities, completion

of coursework, development of study skills, any modifications or assistance needed in order to learn material.

Case Study #1

Male emerging adult between the ages of 18-25 with dyslexia. He was a first year student at The Ohio State University, taking his first collegiate course. He received no readily identifiable support from family. Subject was completing volunteer work with a sports team on campus at the time and did not have paid employment. His varied interests included exercise science, physical education teaching, coaching, and English. He had not yet chosen a major due to the combination of his varied interests and his indecisiveness about precisely what he wanted to do.

His personality was extroverted and friendly. In addition, he was easily distracted by friends and social events. He prioritized spending time with friends over working on classwork. As a result, much of his work was not completed on time. In addition, his goals that were outlined at the beginning of the semester regarding coursework completion were not consistently met.

It was observed that subject was unsure how to complete longer assignments as well as study for tests and quizzes. This resulted in incomplete assignments and poor performance on tests. He was willing to discuss these discrepancies only after educational coach inquired about them. This was the trend continued until mid-semester. When questioned about specific supports he needed, he was able to articulate his needs. For example, he was aware that he was a very visual learner and therefore asked for help in structuring his notes by color when studying for tests.

There was an increase in the subjects advocating for needed supports that was directly congruent with the increased level of social interaction he had with educational coach.

Interactions with educational coach at the beginning of the semester were very structured around only providing only academic support. As the semester progressed, the structured role of education coach began to blur and transformed into a peer mentor who also provided academic tutoring. This was due to the increased level of familiarity between the educational coach and subject.

In relation to interactions with similar age peers (with disabilities as well as without disabilities) he was very open, engaging and inviting. However it was observed that preference was toward capitalizing upon behavior similar to peers without disabilities in academic classroom settings. Also, it was observed that although he was willing to converse with peers in audited course, it took time for the peers to comfortably reciprocate communicating with him.

This behavior became apparent at the beginning of every class period. The classroom was locked and as a result the subjects' peers who arrived early had to stand outside of the room until the professor came. During this time, the subject and educational coach would discuss sports and athletes. His peers would watch the interactions between the educational coach and subject. After a few weeks of observing their interactions, the peers began to initiate conversations with subject about sports on their own. The educational coach served as a model for which the peers could modify their behavior after.

Case Study #2

Male emerging adult between ages 18-25 with autism. He received more than moderate support from family. Mother was actively involved in his participation in TOPS program. He was a first year Ohio State transfer student who left previous institution due to anxiety about

managing course load. He had a friendly, introverted personality, and was not very social although he did express a desire to meet more people.

He did have paid employment at the time; however the job was not in line with his academic interests. His academic interests included subjects in the hard sciences, such as meteorology or biology. Furthermore, he knew he wanted to pursue a major in aviation. He completed his coursework on time and succeeded in consistently meet his semester goals outlined at the beginning of the semester.

Observations showed that supports that focused on social skills were necessary. There are two examples to illustrate this. First, subject would insert comments or ask questions that were not relevant to topic at hand in an effort to actively contribute to class discussions. This resulted in the class becoming distracted. However, he was not aware of this because he just thought he could ask or say anything that he was curious about. The educational coach explained to him how his questions interrupt the classes lecture, as well as what the appropriate questions are and when is the appropriate time to ask questions.

Second, during a weekly meeting with participant, he expressed an interest to understand the dynamics of friendships and how one makes friends. The topic was diagrammed on the board by the education and discussed in detail with subject. As a result, subject possessed a social skill that he could use in the future.

In audited course, observations showed that there was little preference for subject to assimilate his behaviors with that of his peers. However it was observed that the subject had a realistic awareness of his disability and that it set him apart. For example during a weekly one hour meeting, he expressed frustration at the fact that he knew he had to take naps during the day, because sleepiness was a side effect of the medication for his disability.

He expressed a desire to not have his disability at all and lamented the fact that his disability made him different. Nevertheless, his interactions toward peers he was familiar did not vary from those he was unfamiliar with. He was interested in engaging in conversation with anyone who was open to speaking to him. Peers appeared open to conversing with him and did not seem disturbed by his disability.

Results and Conclusions

The literature in the introduction stated that it is beneficial for the individual to disclose their disability as needed. However the results of this study proved otherwise. Although both subjects possessed an internal self-awareness of their disability, their behavior externally showed a displacement of their disability.

These behaviors could be attributed to the subjects' differences in contextual or environmental factors such as: personality, familial support, level influence from peers, and coping style. The influence of these factors on disability could be explained by the International Classification of Functioning, Disability, and Health (ICF) model. The ICF model attests that the level of individual functioning is dependent upon those factors and not on the disability itself (International Classification of Functioning, Disability, and Health, 2014). Although there is a strong possibility of correlations between the ICF model and the treatment of disability, closer examinations are beyond the scope of this project.

Now the internal self-awareness manifested itself through the subjects' acknowledgement of the presence of their disability, as well as the strengths and limitations the caused by the disability. This could be attributed to an increased focus on self, which is a feature of emerging

adulthood outlined in the introduction. However the most important aspect of the findings was the external displacement of the disability from their identity.

Reasons for this displacement could also be attributed to the emerging adulthood characteristics of increased possibilities and feeling being in between. Both subjects were novices in a higher academic setting, in sense that they were first year students at Ohio State who had very little previous experience in a higher academic setting. Being a novice of this type of setting fostered a greater number of possibilities for personal development apart from the disability. Subject one was indecisive when choosing a major, was decisive about embracing the possibilities for increased social interactions. Subject two was in an unsatisfactory place of employment, and was open possibilities of finding a better suited job.

In addition to exploring the reasons behind displacing disability, it is also important to illuminate the fact that the disability was being displaced. There was discontinuity between the skills taught to the subjects by the TOPS program and the actual behavior of the subjects in actual social contexts. Although the program taught them to self-advocate as needed, the studies showed that they did not consistently advocate for themselves but rather waited for their support to initiate aide.

Furthermore, evidence of this discontinuity also showed in role of the educational coach. Instead of the educational coach providing structured academic support, the role began to transform as the semester progressed into that of a peer model. There is a possibility the peer modeling provided an opportunity for maturation and for the subject to gain a deeper understanding of what it means to be an emerging adult. Further studies could be done that center around this insight.

Finally, it is important to note that helping the subject become aware of the strengths and limitations that accompany having a disability does not necessarily equate the acceptance of the disability. Similarly, giving the subject the opportunities to advocate for themselves and ask for support as needed, does not necessarily equate them actually being comfortable disclosing their disability. I believe the development of disability in relation their identity externally displaced during emerging adulthood. I also believe that this behavior, which may not be not all encompassing of emerging adults with disabilities, is subject to change. Just as the stage of emerging adulthood is temporary, it is possible the perspective of disability these individuals have in relation to their identity is temporary as well.

Future considerations

Future case studies could further examine the incongruence between self-advocacy skills taught by the program and actual behavior in social contexts. The sample size for this project was quite small, however case controlled studies designed in programs similar to that of the TOPS program in the future. This would in turn result in a larger sample size. The results of these studies could be obtained through written questionnaires done by the participants support team, which includes the students who observe them in class and work as well as the individuals who coordinate their individualized meetings. In addition, these questionnaires could be incorporated into the weekly paperwork evaluations of the student supports, and into the goals discussed in the individualized biweekly meetings. For example, throughout the semester the student supports could record their observations about the participant's actions, as well as the reactions of peers around them.

The recorded material could be compared to earlier material to document similarities and differences from the earlier observations. These recorded documents could also be used to qualitatively analyze factors that play into the decisions these emerging adults make about their disability and why they make them. Furthermore, the results obtained can be compared to the research already completed on emerging adult without disabilities.

These questionnaires and observations will yield data that has multiple benefits. They will be a significant contribution a field of study that is still developing. They also could serve as a stepping stone into further solidifying of the framework of programs similar to the TOPS program at Ohio State University. Programs that strive to emphasize their participant's strengths, whilst working through their limitations. Furthermore, it will aid families and support staff in the understanding of what the emerging adult with a disability is going through and may provide an explanation for their behaviors.

References

- Arnett, J.J., & Tanner, J.L. (2006). *Emerging adults in America: Coming of age in the 21st century*. Washington, DC: American Psychological Association.
- Arnett, J.J. (2002). *Readings on adolescence and emerging adulthood*. Upper Saddle River, N.J. Prentice Hall.
- Garland-Thomson, R. (1997). *Extraordinary bodies: Figuring physical disability in American culture and literature*. New York, New York: Columbia University Press
- International Classification of Functioning, Disability, and Health (ICF). (2014). *WHO*. Retrieved from http://www.who.int/classifications/icf/icf_more/en/
- Rubin, H.A. (Director). (2005). *Murderball* [Documentary]. United States; EAT Films LCC:.
- Siebers, T. (2008). *Disability theory*. Ann Arbor, Michigan: University of Michigan Press.
- Solomon, A. (2012). *Far from the tree: Parents, children and the search for identity*. New York: Scribner.
- Solomon, A. (2013, April). *How does an illness become an identity?* TEDMED. Retrieved from

<http://www.tedmed.com/talks/show?id=64604>

TOPS Program Transition Services.(2014). *Welcome to the Nisonger Center!*. Retrieved from
<http://nisonger.osu.edu/specialed-transition/tops>